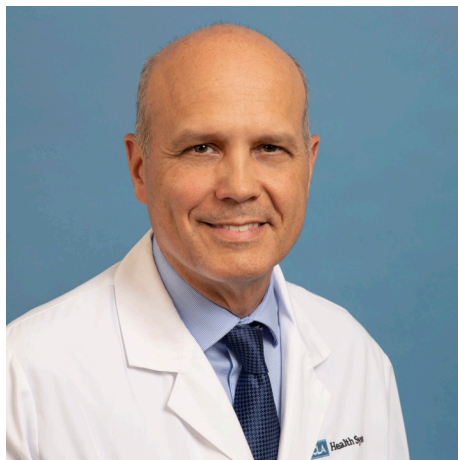


Ahmanson/UCLA

Adult Congenital Heart Disease Center

FOR THOSE TOUCHED BY CONGENITAL HEART DISEASE

Winter 2018



Dr. Glen Van Arsdell

CENTER UPDATES

UCLA welcomes Dr. Glen Van Arsdell as Chief of Congenital Cardiac Surgery

We are pleased to welcome Dr. Glen Van Arsdell, one of the world's leading congenital cardiac surgeons, as the Chief of Congenital Cardiac Surgery at UCLA. Dr. Van Arsdell previously served as the Chief of Cardiac Surgery at the Hospital for Sick Children in Toronto, one of the largest congenital cardiac surgery programs in North America. His career began at Loma Linda University Medical Center, where he received

his medical degree and completed his surgery residency and cardiothoracic surgery fellowship. He then moved to Toronto, completed additional training in congenital cardiac surgery before joining their surgical faculty in 1996. He quickly developed a reputation as an outstanding congenital cardiac surgeon, equally as adept at the complexities of cardiac surgery in newborns as he was in operating on the sickest adults with congenital heart disease. By 2001, he was Division Head of congenital heart surgery at the Hospital for Sick Children, later becoming University Division Chair. He has routinely been invited to speak at international meetings on ACHD and is recognized by his peers for his expertise in congenital cardiac surgery across the lifespan.

Dr. Van Arsdell's academic work is currently focused on developing patient specific precision surgery for Tetralogy of Fallot. Towards this end, he currently has two PhD candidates conducting research studies in Tetralogy including a global enrollment study. Dr. Van Arsdell has received several grants for his research endeavors and has co-authored over 200 peer-reviewed manuscripts on various aspects of congenital heart surgery. Dr. Van Arsdell is a master teacher, and he has spearheaded the use of 3D printing as a means of improving surgical training. He also has an interest in the development of event based databases for program management, and as a tool for determination of best clinical practices.

We are fortunate that Dr. Van Arsdell has returned to California as a Bruin! Please join us in welcoming Dr. Van Arsdell to UCLA; we look forward to working with him closely to continue to provide world class care to our ACHD patients.

New ACHD Guidelines Published!

The 2018 ACC/AHA Guidelines for Management of Adults with Congenital Heart Disease were published in August. This is a valuable resource for all healthcare providers caring for adults with CHD, and serves as the standard for ACHD care. Dr. Jamil Aboulhosn was a member of the writing committee for the 2018 guidelines.



Dr. Jamil Aboulhosn receiving the Sherman Mellinkoff Faculty Award

Jamil Aboulhosn awarded Sherman Mellinkoff Faculty Award in June 2018.

Dr. Jamil Aboulhosn was presented the Sherman Mellinkoff Faculty Award at the David Geffen UCLA School of Medicine annual commencement ceremony on June 1, 2018. The award, (established in 1979) recognizes the finest in doctor-patient relationships, medical education and is the highest honor bestowed on a physician by the medical school at UCLA. One of its past esteemed recipients was Dr. Joseph Perloff, our founding director, who received the award in 2000. We congratulate Dr. Aboulhosn on this accomplishment, recognizing the importance of a caring patient relationship, while teaching our next generation of medical providers and transforming the field of adult congenital heart disease through innovation and research.

UCLA ACHD in the Community

Porter Ranch, Santa Clarita and Thousand Oaks

The Ahmanson/UCLA Adult Congenital Heart Disease Center is proud to announce monthly ACHD clinics with Dr. Aboulhosn at the UCLA Health offices in Porter Ranch, Santa Clarita, and soon Thousand Oaks. Please contact our office at 310-794-5636 or email us at achdc@mednet.ucla.edu if you are interested in scheduling your next appointment at one of these locations.

[Faculty and Contact Information](#)

Faculty

Ahmanson/UCLA ACHDC Faculty

Jamil Aboulhosn, MD, Director, Streisand Chair, Congenital Cardiology and Interventional Cardiology

Leigh Reardon, MD, Congenital Cardiology

Jeannette Lin, MD, Congenital Cardiology

Gentian Lluri, MD, PhD, Congenital Cardiology

John Child, MD, Emeritus Director

Daniel Levi, MD, Interventional Cardiology

Kevin Shannon, MD, Electrophysiology

Jeremy Moore, MD, Electrophysiology

Kalyanam Shivkumar, MD, PhD, Electrophysiology

John Moriarty, MD, Interventional Radiology

Paul Finn, MD, Cardiovascular Radiology

Pierangelo Renella, MD, Cardiovascular Radiology

Surgical Faculty

Glen Van Arsdell, MD, Chief of Congenital Cardiovascular Surgery

Hillel Laks, MD, Congenital Cardiac Surgery

Reshma Biniwale, MD, Congenital Cardiac Surgery

Richard Shemin, MD, Chief, Division of Cardiac Surgery

Nursing Staff

Mary Canobbio, RN, MN, Transition and Pregnancy Nurse Specialist

Pamela Miner, RN, MN, NP, ACHD NP

Katrina Whalen, RN, MSN, NP, ACHD NP

Vanessa Kalis, RN, DNP, ACHD NP

Jennifer Doliner, RN, BSN, Nurse Coordinator

Nicole Antonville, RN, MSN, Nurse Coordinator/Transition Educator

Administrative Staff

Veronica Olmedo, Clinical Coordinator

Yvonne Jose, Administrative Manager

Adriana Magallanes, Physician Support Representative

Andrew Yuen, Program Manager

Marzetta Crawford, Administrative Assistant

Social Work

David Highfill, LCSW

Research Coordinators

Anisha Fernando

Soraya Sadeghi

Contact Us

Patient Scheduling (310) 825-9011

Nurse Coordinator (310) 794-5636

Fax Numbers (424)-465-6189 or (310) 825-9012

E-mail: achdc@mednet.ucla.edu

Website: <http://heart.ucla.edu/ACHDC>

Information & Resources

Adult Congenital Heart Association (ACHA)

Website: www.achaheart.org

Call (888) 921-ACHA

Email: info@achaheart.org

STAFF INTRODUCTIONS

We are delighted to welcome the following new members to the UCLA ACHD Team!

Vanessa Kalis, DNP



Vanessa Kalis joins our ACHD nurse practitioners, bringing a wealth of experience from her prior work as a nurse practitioner in electrophysiology and pediatric cardiac surgery. Prior to joining us, she worked in the cardiac intensive care unit at the Children’s Hospital Orange County and at Rady Children’s Hospital San Diego. She has been an invited speaker at numerous conferences for nurse practitioners and other advance practice clinicians nationally and internationally. She is a fearless world traveler, and enjoys seeking new adventures in remote corners of the world!

Andrew Yuen



Andrew Yuen joined us in 2017 as the Program Manager for the Ahmanson/UCLA ACHD Center. He received his undergraduate degree in business economics at UC Santa Barbara. He has been a part of the UCLA family since 2010, working in the offices of several medical specialties, and with the UCLA School of Medicine before joining our program. He has been an invaluable addition to our team! He enjoys rooting for the Sacramento Kings and San Francisco 49ers, as well as traveling and relaxing with friends and family.

Marzetta Crawford



Marzetta Crawford joined the team as an Administrative Assistant in August 2018. Marzetta has been working as an administrative assistant in several of the primary care and specialty clinics for UCLA for over five years. She brings her vast knowledge and expertise in patient scheduling and insurance issues. When not working, she enjoys going to concerts, parades, listening to music, and spending time with her family.

Nicole Antonville, RN, MSN



Nicole Antonville recently joined us in October 2018, holding a dual role as a nurse coordinator for the ACHD Center and an educator for patients transitioning from pediatric cardiology to adult congenital cardiac care. She received her Masters of Nursing in 2010 from the UCLA School of Nursing, after receiving her Bachelor’s degree in Psychology. Nicole has worked in the UCLA Coronary Care Unit at Ronald Reagan UCLA Medical Center for the last 8 years, often caring for our ACHD patients. She looks forward to using her clinical expertise in the outpatient setting in her new position. During her free time, she enjoys spending time outdoors with her growing family and practicing yoga.

Adam Small, MD



Dr. Adam Small joined the ACHD team in July 2018 for a two-year subspecialty fellowship dedicated to the care of ACHD patients. His kindness and warm bedside manner have already been noticed by many patients! He received his B.A. degree in psychology and M.D. degree from the University of Pennsylvania. He became interested in the field of ACHD as a medical student, and completed a combined medicine and pediatrics residency at the University of Pennsylvania. Having learned of the Ahmanson/UCLA ACHD Center, he then chose to pursue his cardiology and ACHD fellowships at UCLA. Adam is an accomplished athlete, having completed several marathons. When he is not at UCLA, Adam enjoys spending time with his wife Emma and their newborn daughter Layla.

Weiye Tan, MD, MPH



Dr. Weiye Tan also joined the ACHD team in July 2018 for a two-year adult congenital heart disease fellowship. He received his B.S. degree in Biology and M.D. degree from Duke University, and received an MPH from University of North Carolina Chapel Hill. He then completed a combined medicine and pediatrics residency at UCLA, and has remained a UCLA Bruin for his cardiology and now ACHD fellowships. His dedication to the care of individuals with congenital heart disease is second to none, and he shares this enthusiasm volunteering as a counselor at Camp Del Corazon (summer camp for children with heart disease), where he is known by his camp name, “Junior Mint.” He also enjoys playing soccer and golf, and skiing.

Congratulations to Linda Houser on her Retirement!



Linda Houser, RN, MSN, NP

In July, we bade farewell to retiring nurse practitioner Linda Houser, as she left UCLA after devoting 15 years to the ACHD Center. Linda’s compassion and singular dedication to the wellbeing of her patients will be the trademark of her impressive career. She will most definitely be missed and expresses her own heartfelt farewell in a personal message below:

Dear Friends,

It was with mixed emotions that I retired from UCLA on July 1st, drawing the curtain on a 31 year career--half of which was spent as a nurse practitioner with the UCLA Adult Congenital Heart Disease Center. When I started my job with the Center, I had no idea that it would be my one and only nurse practitioner job at UCLA. Yet looking back through the years, I would not have had it any other way.

It has been an honor and a privilege to serve the UCLA ACHD community--to provide care, to teach, to learn, to share in joys, successes and accomplishments, to help in times of stress, fear, uncertainty and sometimes tragedy, to see babies born, hear about new careers in the planning and yes, to watch many of YOU enter retirement! I have learned much, and have witnessed the true nature of the human spirit through the strength, humor, determination, courage, and optimism exhibited by all of you. Thank you for your kindness, patience, understanding and support through the years. My memories of UCLA ACHD will last a lifetime, and wherever my future path leads, I will keep you all in my heart.

Success, peace and prosperity to all.

With deepest appreciation,

Linda

Faculty Profile – Gentian Lluri, MD, PhD



Dr. Gentian Lluri

Dr. Gentian Lluri started his career at UCLA as an ACHD cardiologist in July 2016, and with his warm and friendly demeanor, he rapidly gained the respect and devotion of his patients and colleagues. His European roots in Albania provided an impressive foundation in many languages, including French, Italian, Spanish, and Albanian. He attended medical school at University of Vermont College of Medicine where he completed the MD and PhD programs. He completed his internal medicine residency at University of Illinois at Chicago, followed by general cardiology fellowship at UCLA where he also served as chief fellow, before embarking on his ACHD fellowship. Since completing his training in 2016, Dr. Lluri has become invaluable to the ACHD team as a dedicated and skilled clinician and researcher. Dr. Lluri has a long-standing interest in understanding the pathways that lead to abnormal cardiac development and congenital heart malformations. His research work at UCLA has led to better understanding and advancement of treatment strategies for a variety of congenital malformations in the adult population. Such findings have been presented nationwide and published in the scientific literature.

Besides Dr. Lluri’s work as a clinician and researcher, he regularly and frequently lectures residents, fellows, and other clinical care providers on different ACHD topics.

On a personal note, when not taking care of patients, Dr. Lluri enjoys spending time with his family and exploring the city with his wife and two little boys.



Roslyn, 35yrs old

Following My Heart

As the citywide speakers playing the “call to prayer” in Arabic awake me, I find myself yet again reflecting on how my life has led me to be in Iraq. Having grown up in a suburb of Los Angeles and attended private school my entire life, I think I grew up sheltered from the real world. This was probably because my parents wanted to keep me safe from harm, as would any parents who heard the words “congenital heart defect” to describe their newborn baby.

In July 1983, one day after I was born, a doctor heard a murmur when performing my newborn check. I was diagnosed with partial atrioventricular septal defect. Doctors were hopeful that the hole in my heart would close on its own, so I went home after a few days with my very worried parents. They took me to annual cardiology appointments, yet at the age of three I ended up in heart failure. The week of Thanksgiving 1986, I had my first open heart surgery to patch the hole in my heart at Children’s Hospital Los Angeles.

Home from the hospital in a week, I continued my childhood without any medical problems. At nine years old, I again found myself in heart failure, even though I had been seeing my cardiologist annually. After recovering from a cold, I had a persistent cough that was actually an overlooked symptom of congestive heart failure due to a leaking heart valve. Three days after my 10th birthday, I was at Loma Linda University Children’s Hospital undergoing my second open heart surgery to replace my severely malfunctioning mitral valve. Carefully weighing the options, my parents chose to have the surgeons place a mechanical valve instead of a bioprosthetic pig valve. Living with a mechanical valve meant that I would have to take an anticoagulant medication, Coumadin, daily for the rest of my life. At the time, placing mechanical valves in children was very new, and the surgeons estimated that the valve would last around twenty years. On the other hand,

they believed a pig valve would likely require another surgery within five years. In July 2018, I celebrated 25 years with the same mechanical valve ticking proudly inside my chest!

But how did this all lead me to Iraq? Well, I can say I literally followed my heart there. During my hospitalization at 10 years old, I determined that I wanted to become a nurse when I grew up. I was fascinated in learning about all the medical equipment and medications. Most vividly, I remember never being in pain, a direct result of the excellent nursing care I received. Excited to start my career, I graduated from college with my Bachelor’s degree in Nursing by the age of 21. After gaining several years of knowledge in the Pediatric ICU, I began travel nursing, and have worked in over a dozen children’s hospitals across the US. With the flexibility of travel nursing, I explored the option of joining medical mission trips in need of nurses with my expertise.

In 2012, I found my true passion, in life and in my career - I began volunteering with a nonprofit organization that travels to developing countries to provide cardiac care and surgery to children in need, and educate local teams. Upon witnessing the lack of medical care, specifically pediatric cardiac care in the developing world, I realized I might not have survived childhood had I been born elsewhere. Feeling compelled to continue to help more children with CHD in developing countries, I have since traveled to Ecuador, Ukraine, Russia, Libya, Iran and of course, Iraq. Since 2014, I have held the role of PICU Nurse Educator and Coordinator with the William Novick Global Cardiac Alliance. The true mission of our medical trips is to educate local teams and build sustainable pediatric cardiac programs, so that children with CHD worldwide can have healthcare solutions and can survive.

For the past six years, I have volunteered with Camp Del Corazon as a Med Nurse and Nurse Coordinator. I administer the medications to the campers and ensure their safety as they enjoy the activities offered at camp. The magic of camp is inspiring, witnessing these children doing activities that they’ve been told they “can’t.” It is through Camp Del Corazon that I met my future husband, whose own unique heart story brought us both together in life.

In July 2018, I became employed by the UCLA Children’s Heart Center as an Outpatient Nurse Coordinator. Working alongside some of the doctors I first met while volunteering at Camp del Corazon, I am caring for pediatric cardiac patients and their families as a whole. My passion for pediatric cardiology has flourished through helping these individual families close to home.

Additionally, I have traveled to Washington DC twice to share my story with legislators. On Capitol Hill, I joined the Adult Congenital Heart Association to advocate for CHD

awareness and funding. Through witnessing the worldwide impact of CHD, I believe that our country can and should be at the forefront of pediatric and adult congenital heart care. For several years, I have been an active member of the Adult Congenital Heart Association. Beginning in January, I will be an ACHA Heart to Heart Ambassador, proving peer support and serving the community on behalf of ACHA.

While my heart defect does not define me, it has truly determined the direction of my life. With the guidance of my adult congenital cardiac team at UCLA, I am managing my own health and feel like an active member of my healthcare team. Taking responsibility of my own health has allowed me to live the life I choose. I feel confident traveling internationally, hiking alone up mountains, and spreading CHD awareness. I know that ultimately my heart, defect and all, is leading me on my journey through life.



Marcy, 53 yrs old

Living Life

In Memorium
Written by Marcy’s husband Ron

Marcy was born in June of 1964 with Truncus Arteriosus Type 1, severe pulmonary hypertension with Eisenmenger Syndrome and was given three or four months to live. But don’t let that description of her heart condition make you think that Marcy ever let that stand in her way from “Living Life.”

Her mother (a nurse) and father (an airplane mechanic for a commercial airline in Denver, Colorado) cared for her with all their love, but not as a child that needed to be coddled. I heard more than once that as a child growing up, Marcy had to be told to slow down and rest. This is not to say that her parents and her

older siblings didn’t watch over her, because they did.

Fast forward to 1993 and that is when I met Marcy on a blind date. From the moment I met her, I knew this woman was a special person and I wanted to spend the rest of my life with her. Soon after that first date, Marcy fell ill and the next thing I knew we were at the UCLA Adult Congenital Heart Disease Center seeing Dr. Joseph Perloff and Pamela Miner, NP.

In our 24 years of marriage, Marcy never let her heart condition dictate to her but rather she dictated what her life was going to be. Marcy was always on the go, even though her normal oxygen saturations were around 75% to 80%. She loved to swim, ride her bike, volunteer at hospitals, our church and wherever she saw a need. She also had the uncanny ability to volunteer me when somebody needed help. Marcy was heavily involved in our community upgrades and spent countless hours working with the Amenity Advisory Committee. Marcy never let her health slow her down, she met life head on with love and care for others. Most times putting others needs before her own.

Marcy also had a passion for travel. During our time together, we were fortunate to have the opportunity to visit over 20 different countries and meet people from all parts of the world. A fitting saying that defines Marcy’s love of life and travel, “The best things in life are the people we love... the places we’ve been... and the memories we’ve made along the way.”

Of course, there were those times where Marcy needed to be hospitalized and receive the necessary care from highly specialized doctors. Those hospital stays never slowed her down; it only made her want to do more. In January of 2018, we again found ourselves at UCLA, this time with Dr. Jamil Aboulhosn and NP, Pamela Miner. Marcy’s health condition was at a point in her life where the need for a medical procedure was warranted. Marcy resigned herself into the hands of another and did so completely where there was perfect trust. She was confident that God would answer her prayers and was sure that God had chosen to love her and would lovingly meet her needs. God answered her prayers.

Marcy suffered a fatal complication during her high risk cardiac cath procedure, and passed away on March 29, 2018. Marcy donated her heart to the doctors of UCLA in the hopes that it would help benefit future patients with congenital heart diseases. Unique in her own ways, in the heart, soul and inner gifts she shared throughout our days, Marcy’s love of life was a miracle whom no one can replace and who to this day gave us special memories that time cannot erase.

2018 Joseph K. Perloff Lectureship awarded to Dr. Ariane Marelli



Dr. Ariane Marelli receiving the Joseph K. Perloff Lectureship Award

In February 2018, the Ahmanson/UCLA Adult Congenital Heart Disease Center invited Dr. Ariane Marelli to UCLA as the 2018 Joseph K. Perloff visiting professor. Dr. Marelli presented “Changing Demographics of Congenital Heart Disease in the 21st Century: Impact on Health Services and Outcomes” to an audience of cardiologists, fellows, house staff, and nurses.

Dr. Ariane Marelli is a world-renowned expert in adult congenital heart disease and currently serves as the Director of the ACHD center at McGill University in Montreal. She is recognized as a world authority on the epidemiology of congenital heart disease. Dr. Marelli completed her ACHD fellowship in 1992, under the mentorship of Dr. Joseph Perloff at UCLA and holds the esteemed honor of being the first ACHD fellow trained at UCLA. In Dr. Perloff’s memory, and honoring his legacy as the founding father of adult congenital heart disease, this annual lectureship carries his name, and seeks to spotlight world-class ACHD cardiologists and cardiac surgeons.

ACHD Research Updates

The Ahmanson/UCLA ACHD Center is currently involved in numerous clinical trials and research studies. We are actively seeking patient participants, so if you would like more information about the following clinical research please contact your ACHD doctor or our research coordinators, Anisha Fernando and Soraya Sadeghi at 310-825-5950.

- Transcatheter pulmonary valves: safety and effectiveness
- Atrial septal defect and ventricular septal defect transcatheter occlusion devices: safety and effectiveness
- Pulmonary vasodilator medication (Macitentan) use in Fontan patients: safety and effectiveness
- Use of feraheme contrast MRIs in Fontan patients
- Blood hepatic factor role in resolution of pulmonary blood vessel malformations

Breaking News:

UCLA publishes important research

- Ghobrial J, Aboulhosn JA. Transcatheter valve replacement in congenital heart disease: the present and the future. 2018 Feb 28.
- Wadia SK, Lluri G, Aboulhosn JA, Shivkumar K, Reemtsen BL, Laks H, Biniwale RM, Levi DS, Salem M, Moore JP. Ventricular arrhythmia burden after transcatheter versus surgical pulmonary valve replacement. Heart. 2018 Apr 10. pii: heartjnl-2017-312769.
- Lindsay I, Nik-Ahd F, Aboulhosn JA, Moore JP. Electrophysiology and structural interventions in adults with congenital heart disease: Comparison of combined versus separate procedures. J Cardiovasc Electrophysiol. 2018 May 18.
- Moore JP, Cho D, Lin JP, Lluri G, Reardon LC, Aboulhosn JA, Hageman A, Shannon KM. Implantation techniques and outcomes after cardiac resynchronization therapy for congenitally corrected transposition of the great arteries. Heart Rhythm. 2018 Aug 18.
- Reardon LC, DePasquale EC, Tarabay J, Cruz D, Laks H, Biniwale RM, Busuttil RW, Kaldas FM, Saab S, Venick RS, Lin JP, Nsair A, Deng MC, Ardehali A, Cadeiras M, Ivengar A, Aboulhosn JA. Heart and heart-liver transplantation in adults with failing Fontan physiology. Clin Transplant. 2018 August.

Counseling & Therapy Services for ACHD patients & families:



David Highfill, LCSW

Our ACHD Social worker David Highfill, LCSW is available for supportive counseling and therapy sessions in our ACHD clinic, 100 Medical Plaza, Suite 630 East, the same clinic where you see your cardiologist. David's clinic hours on Mondays and Thursdays from 9:00 am to 4:00 pm. A few common reasons why ACHD patients benefit from counseling services include:

- Coping mechanisms and behavioral therapy to address anxiety
- Management of depression and identifying need for pharmacologic treatment
- Facilitating successful transition to autonomous adult health maintenance

To schedule an appointment with David or find out more about this service, please email ACHDScheduling@mednet.ucla.edu and copy David Highfill DHhighfill@mednet.ucla.edu or call our nurse line at (310)794-5636.

ACHD Support Group

We are proud to maintain the UCLA ACHD Monthly Patient and Family Support Group, now entering its third year. The group meets in the evening of the last Thursday each month. With the continuing technological developments of CHD treatment, the adult congenital population continues to grow. As CHD patients are living longer, we continue to face the challenges of managing chronic illness in addition to the regular changes we face through the aging process. Managing your changing individual, family, social, economic, and health issues in today's uncertain climate can be frustrating and at times overwhelming. Having the opportunity to meet with other patients and their family members dealing with similar issues and having similar diagnoses can be extremely helpful. Some beneficial effects of participating in a support group include:

- Learning and sharing with other CHD patients and their loved ones can be reassuring
- Group connection provides a unique sense of camaraderie.
- Meeting others with similar diagnoses and issues can help build confidence and self-esteem while simultaneously adding to your overall support system.
- Participants share real-life situations that many CHD patients face (surgeries, procedures, etc)
- Lifestyle coping is a focus of discussions, such as preparing for and adjusting to school or work, how to discuss your CHD, medications, and scars with others, preparing for major stepping stones such as dating, marriage, and whether or not to start a family.
- Group discussions can focus on navigating insurance options, understanding your hospital bills, even when to consider disability benefits.
- Group members often share articles, websites, and other resources offering additional information.

Our ACHD social worker David Highfill is the group facilitator. David is not just another medical social worker but is also a CHD patient who underwent a modified Fontan procedure in 1990 and received a heart transplant in 2012, both here at UCLA. David may have direct personal experience that relates to your situation in addition to his training as a licensed clinical social worker.

The group is open to all Adult Congenital Heart Disease patients and their family members. When planning to attend, we ask that you please RSVP to our office manager Yvonne Jose at (310) 825-2019 or YJose@mednet.ucla.edu as space is limited. To increase group participation, we recently added phone and video conferencing to the support group allowing us to include patients who are not easily able to come to UCLA in person. We are also planning to feature information sessions from the ACHD cardiologists at future meetings. Stay tuned for these announcements.

If you would like to be added to the ACHD Support Group mailing list or have questions about the group, please send your contact/email information to Yvonne Jose.

The 2018 Greater Los Angeles Congenital Heart Walk



Team UCLA, 2018 ACHA Heart Walk

On Sunday, May 6th 2018, the 6th annual Greater Los Angeles Congenital Heart Walk was held in beautiful Griffith Park.

In all, over 1.1 million dollars was raised to benefit the Adult Congenital Heart Association and the Children's Heart Foundation. The event brought together citywide organizations, including UCLA, USC, Cedars Sinai, Children's Hospital of Los Angeles, and Camp del Corazon as well as professionals, patients and their families to share experiences, honor loved ones, listen to music and inspirational speeches, and participate in the 3K or the 5K course.

Regional ACHD Conferences for Patients & Families

The Adult Congenital Heart Association (ACHA) works with regional ACHD providers to organize and facilitate patient education regional conferences nationwide. The objectives are to help adults with congenital heart disease (CHD) and their family members better understand their disease, take an active role in their cardiac care, and connect with their peers and with ACHD medical programs around the county. Through these regional conferences, patients and families have the chance to meet and network with others with CHD and to speak one-on-one with CHD experts and ask questions. This is a unique opportunity for CHD patients and their families, as well as CHD medical professionals. Watch the ACHA website for conferences in your area: www.achaheart.org

UCLA Fontan Survivorship Program

The effects of congenital heart disease on other organs can be profound. This is especially true in patients with severe chronic right heart failure or those with single ventricle Fontan physiology. There is an increasing awareness of the impact of chronic heart problems on liver function and the potentially irreversible liver damage related to congestion and decreased perfusion of the liver. Patients who have undergone the Fontan operation universally develop liver congestion and scarring that worsens over time and eventually may lead to liver failure in some patients. This has spurred UCLA clinicians to develop mechanisms for better understanding, diagnosing and managing combined cardiac and liver disease. Through the generous donation of Ms. Delphine Lee and Mr. Ron Ainsworth, we have developed a multi-specialty program at UCLA to coordinate and promote the diagnosis, management and research into combined heart and liver disease. If you would like to learn more about this important clinical initiative, please visit our website at <http://heart.ucla.edu/ACHDC>



UCLA



CONTRIBUTIONS

How You Can Help

The Ahmanson/UCLA Adult Congenital Heart Disease Center relies on donations in order to pursue many of its goals. This support is vital to the ACHDC's ability to continue providing high-quality care for adult patients with CHD. Jeff Wong (pictured with his brother) is one beneficiary of the highly advanced care we provide at UCLA. He shares his journey to becoming a patient at UCLA:



Jeffrey Wong (Right)

"Your VSD has enlarged. You are going to need surgery as soon as possible -- open-heart surgery." It all happened so fast. Before I could process it, I found myself a week away from scheduled open-heart surgery at my local hospital. Thankfully, I eventually came out of shock and remembered I had a college friend who had become a cardiologist. He recommended I seek a second opinion at The Ahmanson/UCLA Adult Congenital Heart Disease Center. From the get-go, the nurses and doctors at the ACHDC seemed as concerned with putting my mind at ease as they were with treating my heart. They performed the necessary tests and quickly determined I was a candidate for a catheter-based approach to correct my defect. I had been having nightmares about bone-saws and rib-spreaders; instead, I was offered an alternative that seemed nothing short of miraculous. Thanks to the entire ACHDC team, I was out at the movies the second night after my procedure. Just a month after my procedure, I was able to fly across the country to be the Best Man at my brother's wedding."

Your tax-deductible contributions help us provide care for patients like Jeff by directly supporting:

- Patient programs focused on enhancing quality of life, including newsletters, educational websites, support groups, and psychological counseling
- Research programs aimed at extending life expectancy
- Training programs integral to preparing future providers to offer the highest level of care

You can learn more about how to support the ACHDC by visiting heart.ucla.edu/ACHDC and clicking on "ways to give." To discuss specific gift options, or for more information, please call (310) 825-2019.